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AUTHOR Schuster, Clara Shaw, Comp.  
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## ABSTRACT

The annotated bibliography contains 170 citations on factors that affect parental responses to their physically handicapped infants. References are given for the following specific disabilities: blind, cardiac, cerebral palsied, deaf, deaf blind, hemophiliac, mentally retarded, metabolic, neurological, and orthopedic. About 90 citations deal with nonspecified or various disabilities. References usually date from 1965 through 1975, are arranged alphabetically by author within each handicapping category, and include nonevaluative annotations of approximately 50 words each.  
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Selected and Annotated

BIBLIOGRAPHY

on the

REACTIONS OF PARENTS TO PHYSICALLY DISABLED INFANTS

1965 - 1975

Compiled by

Clara Shaw Schuster

R. N., M. Ed.

EC 090374

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## INTRODUCTION

Early childhood education of physically disabled children has been spurred both by public law and growing community awareness of and sensitivity to the needs of these children. Both research and personal experiences are indicating the importance of early childhood experiences and relationships in an individual's total adjustment to life. Professional persons are becoming more aware of the need to include the parents as a part of the habilitation team meeting the needs of the young physically disabled child.

This bibliography is designed to assist the professional person interested in understanding and assisting the parents and families of physically disabled infants. It is primarily limited to pertinent literature published since 1964, although several earlier entries are included because of their uniqueness or classic reference value. It is limited to literature published in English.

This bibliography is not primarily concerned with counseling techniques, intervention strategies or the effect of the disability on the child's self image and development. Its focus is the affective domain of the parents: (a) factors that effect parental response and (b) reactive behavior patterns of the parents in response to the disabled infant.

The bibliography uses a multidisciplinary approach, recognizing that professionals from many disciplines will have contact with these parents. The entries attempt to give a holistic perspective of the stressors parents face with a focus on sociological, interpersonal adjustments facing families as well as psychological, intrapersonal adjustments of the individual parents.

Since this bibliography is prepared for professional persons, all entries are appropriate for multidisciplinary professional reading. Those entries which are focused toward or are appropriate for parents or lay persons are so indicated by (L) following the bibliographic data. Entries which are focused primarily toward medical personnel are indicated by (M). Entries which contain unique or comprehensive data are preceded by an asterisk.

My appreciation is extended to Dr. James Collins, Professor and Assistant Chairman of Education of Exceptional Children, and to Carol Winchell, Research Librarian, both of The Ohio State University, for their supportive encouragement in this undertaking, and to my husband, Richard Schuster, for typing the manuscript.

## Reactions to Specific Disabilities

### Blind

1. "Blind from Birth," Good Housekeeping, Vol 162, No 2 (Feb 66) p 12+. (L)

Personal narration by a mother of twin girls, both blind (RLF) who shares the story of the diagnosis, reaction, behavior patterns, relationships and eventual acceptance. Identifies construction of interventions for positive child, personal and family development. Covers period from prebirth through adolescent years.

2. Bryan, Dorothy. "Guide for Parents of Pre-school Visually Handicapped Children". ED 064819. Springfield, Ill.: Illinois State Office of the Superintendent of Public Instruction, 1972. 65 pgs. (L)

A practical guide written for parents includes brief section on normalcy of negative reactions and importance of positive attitudes to foster child's potentials. Mainly concerned with practical suggestions for approaches to normal developmental task achievement. Comprehensive list of social systems available in Illinois.

3. Byers, Margery. "Only One Twin Can See," Life, Vol 61, No 18 (Oct 28, 66) p 89-92. (L)

Relation of how a mother and father reached and finally accepted diagnosis of blindness in one twin. Practical ideas on how they stimulated development shared.

4. Froyd, Helen F. "Counseling Families of Severely Handicapped Children," The New Outlook for the Blind, Vol 67, No 6 (June 73) p 251-257.

Discussion of factors affecting parental attitudes and parent-child relationship. Relates data to cultural and developmental phenomena. Intervention strategies identified. Illustrated with case study.

5. Kozier, Ada. "Casework with Parents of Blind Children," Social Casework, Vol 43, No 1 (Jan 62) 15-22.

Discusses need for a family-centered approach to working with parents of blind infants that integrates educational data with supportive counseling. Several case studies illustrate long range effect of unresolved grief reactions.

6. Lairy, G. C. and A. Harrison-Covello. "The Blind Child and His Parents, Congenital Visual Defect and the Repercussion of Family Attitudes on the Early Development of the Child," American Foundation for the Blind Research Bulletin #25 (Jan 1973) p 1-24.

Detailed exploration of behavior patterns of blind infants and preschool age children. Related to symbolic meaning of blindness to parents and subsequent parental interaction patterns based on levels of acceptance and involvement. Includes 7 page developmental scale for preschool blind children.

- \*7. Parmelee, Arthur and Lonis Liverman. "Blindness in Infants and Children," in Ambulatory Pediatrics, ed. by Morris Green and Robert J. Haggerty, 1968, p 541-549.

Comprehensive discussion of longitudinal effect of blindness on achievement of development tasks by blind child. Discusses relationship between maternal adjustment and maternal child relationship. Intervention strategies identified.

8. Tait, Perla. "The Effect of Circumstantial Rejection on Infant Behavior," The New Outlook for the Blind, Vol 66, No 5 (May 72) p 139-151.

Indepth discussion of psycho-social development as related to mother-child interaction. Brief discussion of mother's adjustment to disability scattered throughout as related to child's developmental tasks. Well supported by significant development theories.

9. Warnick, Lillian. "The Effect Upon a Family of a Child With a Handicap," The New Outlook for the Blind, Vol 63, No 10 (Dec 69) p 299-304.

General discussion of factors affecting parental acceptance and adjustment to life with blind infant. Identification of stress factors and areas important for counseling.

### Cardiac

1. Jackson, Pat Ludder. "Chronic Grief," Am. J. of Nursing, Vol 74, No 7 (July 74) p 1288-1291. (M)

Hypothesizes that parents of a defective child cannot complete the final phase of mourning (resolution of loss of idealized child) because of the continued care required by the defective child. Discusses variables effecting the parental coping processes and corresponding professional intervention strategies.

2. Linde, Leonard, Beatrice Rasof, Olive Jean Dunn and Ethel Rabb. "Attitudinal Factors in Congenital Heart Disease," Pediatrics, Vol 38, No 1 (July 66) p 92-101. (M)

Exploration of implications of diagnosis of congenital heart defect on child, parents and siblings through 5 years. Developmental analysis of 100 affected children. Tables compare interplay of severity of defect with specific variables. Role of physician in family attitude and role of mother in child's adjustment analyzed.

3. Roberts, Florence Bright. "The Child with Heart Disease," Am. J. of Nursing, Vol 72, No 6 (Je 72) p 1080-84. (M)

Suggests that parental anxiety is transmitted to child and prohibits maximal development of every family member. Explores paternal behavior patterns and effect on cognitive and social development of the child.

4. Rozansky, Gerald I. and Leonard M. Linde. "Psychiatric Study of Parents of Children with Cyanotic Congenital Heart Disease," Pediatrics, Vol 48, No 3 (Sept 71) p 450-451. (M)

Discussion and analysis of dynamics of group discussions with parents of 13 children with cyanotic heart disease. Behavior manifestations - overt and covert - analyzed, related to individual coping, family dynamics and parent-child relationship.

### Cerebral palsy

1. Bavin, Jack. "Parents' Problems," in Handling the Young Cerebral Palsied Child at Home, by Nancie R. Finnie. N.Y.: E. P. Dutton & Co., Inc., 1975, p 12-31. (L)

Discussion of the emotions and questions facing the parents after being told of a child's disability. Exploration of causes of social isolation. Constructive ideas for fostering adaptation to the diagnosis and developmental factors that need to be considered to facilitate play, discipline, independence and individuality. Thoughts on how to achieve a mature, satisfying and mutually fulfilling parent-child relationship shared.

2. Hawke, Wm. A. "Impact of Cerebral Palsy on Patient and Family," The Canadian Nurse, Vol 63, No 1 (Jan 67) p 29-31.

Brief discussion of emotional stressors of parents and siblings of cerebral palsy child. Identification of some of the factors affecting the reactions. Includes section on the effected child's self-image during childhood and adolescence.

3. Hewett, Sheila, John Newson and Elizabeth Newson. The Family and the Handicapped Child, Chicago: Aldine Pub. Co., 1970. "The Impact of Handicap - Some Final Comments," p. 194-207.

Discussion of factors inhibiting maternal acceptance of a child with Cerebral Palsy. Illustrated with case studies drawn from 180 interviews of English mothers. Rest of book (240 pgs.) deals with practical aspects of living with disability. Glossary of terms and interview tool included in appendix.

4. Hosey, Carole. "Yes, Our Son is Still With Us," Children Today, Vol 2, No 6 (Nov-Dec 73) p 14-17+. (L)

A mother discusses her discovery of son's disability and identification of the family's coping powers. Indicates that insensitive professional persons created more stress on the family's ability to cope than the degree of disability itself.



5. "Overprotective Mother," Good Housekeeping, Vol 176 No 4 (Apr 73) p 16+. (L)

Personal narrative of factors aiding a mother to recognize her lack of acceptance of her cerebral palsy child as an individual with capabilities and rights to develop at her own pace.

6. Schleifer, Maxwell J. "Not Enough Time," Exceptional Parent, Vol 4, No 4 (July-Aug 74) p 19-23. (L)

Personal account of responses of nuclear family members to birth of child with Cerebral Palsy. Illustrated with case-study followup.

- \*7. Shere, Eugenia and Robert Kastenbaum. "Mother-Child Interaction in Cerebral Palsy: Environmental and Psychological Obstacles to Cognitive Development," Genetic Psychology Monograph Vol 73, No 2 (May 66) 255-335.

Research presented to analyze quantitative and qualitative aspects of interaction between mother and C.P. children. Observation, case study approach to identify and correlate parental behavior patterns with child's cognitive functioning level. Identifies that severely disabled child is in double jeopardy: (1) lack of maternal gratification by positive responses in infant creates a "vicious circle of mutual frustration" and (2) inability to actualize desired behaviors which in turn enhance cognitive skill development. Offers conceptual, supported framework for ameliorating both factors to facilitate cognitive development and improved family dynamics.

8. Wieder, Daniel and John Hicks. Evaluation of an Early Intervention Program for Neurologically Impaired Children and Their Families. ED 050533. N.Y.: Association for the Aid of Crippled Children, 1970. (28 pgs.).

Final report on a project evaluating effect of group counseling on parental attitudes and adjustment to task of rearing a C. P. child. For analysis, separates attitudes toward child, disability, and self as expressed through identifiable changes in behavior patterns. Holistic approach to effect of parenting on child's development at 9-24 months of age conclude that adjustment process more difficult for, and therapy sessions more successful with mother than father.

### Cleft lip and palate

- \*1. Banks, Mary Jane D. "The Reactions of a Family to a Malformed Infant," ANA Clinical Sessions, 1966, pgs. 69-74. (M)

A nurse discusses how maternal reactions to the physically disabled child may lead to breakdown of adaptive mothering patterns, produce pathological interaction with child. Relationship of inappropriate mothering patterns to physical and emotional illness in child identified and illustrated. Intervention strategies for aiding parents with grief process identified.

- \*2. Battle, Constance U. "The Role of the Pediatrician as Ombudsman in the Health Care of the Young Handicapped Child," Pediatrics, Vol 50, No 6 (Dec. 1972) p 916-922. (M)

In depth discussion of reactions of parents to physically deformed child with implications for physician intervention strategies identified throughout. Illustrated by analysis of family with facially deformed child. Encourages consideration of total child and total family in planning.

3. Clifford, Edward and Eleanor C. Crocker. "Maternal Responses: The Birth of a Normal Child as Compared to the Birth of a Child With a Cleft," Cleft Palate Journal, Vol 8 (July 71) p 298-306. (M)

Study compares 75 mothers with cleft palate babies to 100 mothers of normal infants to explore effect of birth on marital adjustment and sexual satisfaction. Also explores effect of time lapse from birth to seeing child vs. impact of defect on mother and perceived self-image following birth of defective child.

4. Dar, H., S. T. Winter and Y. Tal. "Families of Children With Cleft Lips and Palates: Concerns and Counselling," Developmental Medicine and Child Neurology, Vol 16, No 4 (Aug 74) p 513-517. (M)

Investigation of 51 families of children born with cleft lips reveals that mothers preferred to be told immediately about infant's anomaly and see infant within 48 hours. Explores parental concerns and suggests counseling approaches.

5. Fraser, F.C. and Anne Latour. "Birth Rates in Families Following Birth of a Child With Mongolism," Am. J. of Mental Deficiency, Vol 72, No 6 (May 68) p 883-886.

Compares decline in birth rate in mothers, aunts and aunts-in-law following birth of child with mongolism, cleft lip and palate or hay fever. Indicates that any decline is not statistically significant and that increased maternal age may be a more significant factor than defect.

6. Gibbs, Jeanne Marie. "Cleft Palate Babies: One Mother's Experience," Bedside Nurse Nursing Care, Vol 6, No 1 (Jan 73) p 19-23. (M)

A mother discusses some of her immediate reactions, fears and questions following the birth of a baby with cleft lip and palate. Explores in 3rd person some preexisting factors which effect reactions as well as comments and behaviors of hospital personnel that hampered or aided initiation of positive coping behaviors.

7. Kallaus, Jane. "The Child With Cleft Lip and Palate," Am. J. of Nursing, Vol 65, No 4 (Apr 65) p 120-123. (M)

Explores why mothers go through a grief reaction consisting of 3 phases after the birth of a child with cleft lip. Discusses behavior manifestations of each. Suggests strategies to facilitate resolution of grief of new mother during hospital stay.

8. Penfold, Kathleen McNally. "Supporting Mother Love," Am. J. of Nursing, Vol 74, No 3 (Mar 74) p 464-467. (M)

Discusses the stress of separation as well as cleft lip on the mother-infant bonding process and ways to aid the symbiotic relationship even though mother-infant contact is maintained only through telephone calls (via nurse).

9. Tisza, Veronica B. and Elizabeth Gumpertz. "The Parents' Reaction to the Birth and Early Care of Children With Cleft Palate," Pediatrics, Vol 30, No 1 (July 62) p 86-90. (M)

Exploration of the meaning of a child to the mother. Parental anxieties and needs identified as related to birth of child with cleft palate. Factors affecting maternal coping behaviors analyzed with implications for intervention identified.

### Deaf

\*1. Beasley, Ann, Carol Bogner and Helena Lightel. "Your Child's Deafness: Suggested Readings for Parents of Preschool Deaf Children," American Annals of the Deaf, Vol 117, No 4 (Aug 72) 431-437. (L)

An annotated bibliography for parents covering topics of  
(1) Parent child interaction (2) Parent to parent discussion  
(3) Communication (4) Education (5) Diagnosis (6) Life problems (7) General references and social systems.

\*2. Freeman, Roger D., Susan F. Malkin and Jane O. Hastings. "Psychosocial Problems of Deaf Children and Their Families: A Comparative Study," American Annals of the Deaf, Vol 120, No 4 (Aug 75) 391-405.

Extensive study of 120 prelingually deaf children and their families to identify specific direct and indirect factors affecting the development of the child. Sociological factors explored in depth. Very holistic approach. Limited discussion of specific coping skills of parent. Implications for intervention identified. Extensive supporting recent bibliography.

\*3. Knox, Laura L. and Freeman McConnell. "Helping Parents to Help Deaf Infants," Children, Vol 15, No 5 (Sept-Oct 68) p 183-187.

A presentation of the program of the Bill Wilkerson Hearing and Speech Center in Nashville, Tenn. Explores parental responses to the disability and the need to cope with their feelings before the parent can fully utilize therapeutic approaches with the child. Discusses conflicts parents face in various facets of interaction with others.

\*4. Liversidge, Ellen B. and Gregory M. Grana. "A Hearing Impaired Child in the Family the Parents' Perspective: A Father's Perspective," The Volta Review, Vol 75, No 3 (Mar 73) 175-180.

Discussion of data obtained from group and individual sessions with 12 fathers of young deaf children at Bill Wilkerson Hearing and Speech Center, Nashville, Tenn. Identification of factors which create a discrepancy between the actual and desired involvement of the fathers.

5. Liversidge, Ellen B. and Gregory M. Grana. "A Hearing Impaired Child in the Family the Parent's Perspective: A Mother's Perspective," The Volta Review, Vol 75, No 3 (Mar 73) 174, 181-184. (L)

A mother narrates her thoughts, fears and feelings surrounding the deafening of her young child by meningitis. Followed by discussion of and comparison of the experience with those of other parents including some from literature. Concentration on assessment of the total child and capitalizing on assets.

- \*6. Martin, Veneda S. "What it Means to be the Parent of a Deaf Child," Otolaryngological Clinics of North America, Vol 8, No 1 (Feb 75) p 59-67. (L)

Personal account of a nurse-mother and her problems of adjustment to the diagnosis and life with a deaf child. Attention given to her relationship to professional persons and social systems. Developmental approach to techniques of child rearing unique to deaf child.

- \*7. McAree, Ruth. "What Price Parenthood?", The Volta Review, Vol 72, No 7 (Oct 70) p 431-437. (L)

Very intimate discussion of parental reactions and frustrations to discovery of and living through the early months of a deaf child's life. Generalized description of reactions as well as individualization of reactions identified. Discusses some reasons for hatred of child, (one of the only articles which identifies hate as a normal reaction). Discussion of effect on family relations, coping behaviors, religious beliefs and self esteem of parents. Identification of differences between educating and parenting a disabled child.

8. McKibbin, Elsie. "An Interdisciplinary Program for Retarded Children and Their Families," The Am. J. of Occupational Therapy, Vol 26, No 3 (Apr 72) p125-129.

Discusses necessity of a supportive, interdisciplinary approach to strengthen family members and facilitate positive attitudes toward self and disabled child.

9. Meadow, Kathryn P. "Parental Response to the Medical Ambiguities of Congenital Deafness," Journal of Health and Social Behavior, Vol 9, No 4 (Dec 68) p 299-309.

Analysis of interviews with parents of deaf children for events leading to discovery, confirmation and acceptance of diagnosis. Three stages of reactions of parents in the developmental process of diagnosis are identified and discussed with implications for doctor-parent interaction and transaction. Illustrated with case studies. Discussion well supported by literature review.

10. Mindel, Eugene D. "Deaf Education: A Child Psychiatrist's View," Peabody Journal of Education, Vol 51, No 3 (Apr 74) p153-161.

A psychiatrist discusses factors affecting a deaf child's adjustment to and progress in school as related to adaptation of parents to the disability. Retrospective discussion of early phases of reaction and problems encountered due to incomplete resolution of reactions.

- \*11. Mindel, Eugene D. and McCay Vernon. They Grow in Silence: The Deaf Child and His Family, Silver Springs, Md.; National Association of the Deaf, 1971. "The Impact of the Deaf Child on His Family," p 7-24. (L)

A psychiatrist and a psychologist comprehensively identify factors actively involved in the social and psychological systems of the deaf child's parents and family. Discussion of how these factors may affect identification of the disability, parental adaptation, parent-parent and parent-child relationships. Deals with many of the problems encountered in activities of daily living.

- \*12. Oliver, Rosemary. "The Families of Young Deaf Children," The British Journal of Psychiatric Social Work, Vol 8 No 2 (65) p 27-36.

Brief synopsis of representative family attitudes towards having a deaf child as obtained through interview by a psychiatric social worker. Results of a questionnaire exploring family stress, adaptability and involvement is included. Factors from family of origin as well as current factors are explored as stressors effecting adaptability.

13. Schlesinger, Hilde. "A Child First," The Volta Review, Vol 71 No 9 (Dec 69) p 545. (L)

A psychiatrist discusses for parents, the importance of warm, solid parent-child interaction for the successful development of self esteem and adjustment by the child. Identification of ways to promote positive relationships including acceptance of own negative reaction to disability of deafness.

14. Shepherd, Bruce D. "Parent Potential," The Volta Review, Vol 75 No 4 (Apr 73) p 220-224.

A doctor, father of 2 deaf children, discusses the alienation which is often present between the parents of a disabled child and the trained professional. Explores the effect of this on parental coping and child-parent relationship. Conceptual, holistic approach to how to help child by helping the parents.

- \*15. Shontz, Franklin C. "Reactions to Crisis," The Volta Review, Vol 67 No 5 (May 65) p 364-370.

Schematic presentation and discussion of 5 sequential phases individuals experience when facing a crisis. Each phase is related to self experience, reality perception and the 4 domains of the self system. Conceptually related to parental reactions to child's deafness.

16. Vernon, McCay. "Psychodynamics Surrounding the Diagnosis of a Child's Deafness," Rehabilitation Psychology, Vol 19 No 3 (Fall 72) p 127-134.

Psychologist discusses the psychodynamics surrounding the diagnosis of deafness in a child using a longitudinal time perspective starting with pregnancy. Particular attention to factors inhibiting recognition of disability, misdiagnosis and effect on parent-child relationship. Implications for aiding family communication skills identified.



17. Williams, Pat. "The Fears we Face," The Volta Review, Vol 72 No 5 (May 70) p 303-309. (L)

A mother explores in depth and on a personal level the fears parents of deaf children face and factors aiding or hindering resolution of fear. Sharing of practical problems parents face in communicating with and educating the child. Relation of difficult community incidents precipitated by the child's deafness.

### Deaf-Blind

1. Hammer, Edwin K. Families of Deaf-Blind Children: Case Studies of Stress. ED 084728. Dallas: Collier Hearing and Speech Center, 1973. 17 pgs.

Identification and discussion of parental needs and developmental crisis points. Conceptual approach. Implications for intervention identified.

2. Torrie, Carolyn. Affective Reactions in Some Parents of Deaf-Blind Children. ED 084731. Dallas: Collier Hearing and Speech Center, Nov 72. 13 pgs.

Clinical description and analysis of reactions of parent to birth of and life with a deaf-blind child. Illustrated with case study. Implications of intervention identified.

3. Yu, Muriel. The Causes for Stresses to Families With Deaf-Blind Children. ED 084733. Dallas: Collier Hearing and Speech Center, Nov 72. 15 pgs.

Identification and discussion of medical, economic, emotional and professional factors that can become stressors to parents. Illustrated with case studies. Many implications for prophylactic and amelorative intervention offered.

### Hemophilia.

1. Mattsson, Ake and David P. Agle. "Group Therapy with Parents of Hemophiliacs," Journal of Child Psychiatry, Vol 11, No 3 (July 72) p 558-571.

Affective reactions of parents to having an infant or child with hemophilia as related to therapist during group therapy sessions. Discussion of coping skills used by parents to aid adaptive processes of both parent and child. Follow up. Discussion on value and effect of therapy on parent-child relationship.

2. Salk, Lee, Margaret Hilgarten and Belle Granich. "The Psycho-Social Impact of Hemophilia on the Patient and His Family," Social Science and Medicine, Vol 6 No 4 (Aug 72) p 491-505. (M)

Study of 32 families to identify variables affecting adjustment to living with the disability as differentiated from other disabilities as well as between families. In depth look at sociological factors as well as adjustment over time. Identification of implications for intervention.

## Mentally retarded

1. Berg, J. M., Suzie Gilderdale and Jean Way. "On Telling Parents of a Diagnosis of Mongolism," The British Journal of Psychiatry, Vol 115 No 527 (Oct 69) p 1195-1196. (M)

Study of 95 mothers indicates that most prefer to be informed of a diagnosis promptly -- before they build up false hopes for the child.

- \*2. Erickson, Marcene Powell. "Talking With Fathers of Young Children With Down's Syndrome," Children Today, Vol 3 No 6 (Nov-Dec 1974) p 22-25.

Discussion of factors affecting father's response and coping skills including relationship to parents, community, spouse, medical staff and knowledge about the disability. Illustrated with examples taken from group interviews and counseling sessions.

3. Hersey, William J. "Restoring the Balance," Pediatric Clinics of North America, Vol 20 No 1 (Feb 73) p 221-231.

Conceptual frame offered for understanding and aiding the parents of a disabled child (geared to developmentally delayed infant) restore positive intra- and inter-personal relationships.

4. Mori, Waltraut. "My Child Has Down's Syndrome," Am. J. of Nursing, Vol 73 No 8 (Aug 73) p 1386-1387.

Personal narrative of a nurse who discovers her child is mongoloid. Open account of inner emotions and interrelationships with other persons and child during first weeks after birth. List of agencies to assist parents included.

5. Murphy, Ann and Lois Pounds. "Repeat Evaluations of Retarded Children," Am. J. of Orthopsychiatry, Vol 42 No 1 (Jan 72) p103-109.

A doctor and social worker investigate and discuss why parents of defective children may seek repeated evaluation of child even when diagnosis is clear and financial resources limited. 6 underlying motivating factors identified, 4 of which indicate inability of professionals to meet the needs of the clients. 2 represent difficulty in accepting diagnosis. Offers suggestions to facilitate relationship.

- \*6. Olshansky, Simon. "Chronic Sorrow: A Response to Having a Mentally Defective Child," Social Casework, Vol 43 No 4 (Apr 62) p 190-193.

Discussion of expression of sorrow by parents and factors affecting intensity of the emotion. Implications for counseling explored.

7. Pickworth, K.H. "Mongolism: When Should Parents be Told?," British Medical Journal, Vol 2 No 5424 (19 Dec 64) p 1596. (M)

Medical doctor discusses rationale for telling parents immediately. Suggests that diagnosis may be incorrect. Advocates a deliberate delay to allow mother-infant bonding process to occur.

8. Pinkerton, Philip. "Parental Acceptance of the Handicapped Child," Developmental Medicine and Child Neurology, Vol 12 No 2 (Apr 70) p 207-212.

Presentation and analysis of 7 case studies with identification of core threads and implications for intervention. Exploration of mechanisms underlying rejection of diagnosis.

9. Stone, Nellie D and Joseph J. Parnicky. "Factors in Child Placement: Parental Response to Congenital Defect," Social Work, Vol 11 No 2 (Apr 66) p 35-43.

Research related regarding factors affecting parental decisions to keep child at home or institutionalize defective infant with exploration of long range effects on parental coping behaviors. Implications identified.

- \*10. Zuk, G. H. "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," American Journal of Mental Deficiency, Vol 64 No 1 (July 59) p 139-147.

Since guilt is a significant religious concept, research explores the parental acceptance of a child's disability as reflected in expression or resolution of personal guilt for the disability. Greater emotional support given by Catholic faith appeared to benefit mother and aid acceptance of disabled child. Indicates need to explore religious attitudes as a part of parental therapy.

### Metabolic

1. Bessken, Pauline and Wenda Lee Miller. "A Family Copes With Cystic Fibrosis," Am. J. of Nursing, Vol 67 No 2 (Feb 67) p 341-2. (M)

Presents one family's efforts to cope with the physical and medical stressors unique to caring for children with cystic fibrosis and yet continue to meet the personal developmental needs of each individual member.

2. Keleske, Lorelei, Gerald Solomons and Erica Opitz. "Parental Reactions to Phenylketonuria in the Family," Pediatrics, Vol 70 No 5 (May 67) p 793-798. (M)

Delineation and discussion of emotional stressors encountered by families with PKU child (ren). Data Obtained via questionnaire, analyzed with implications for professional intervention identified.

3. McCollum, Audrey and Lewis E. Gibson. "Family Adaptation to the Child With Cystic Fibrosis," The Journal of Pediatrics, Vol 77 No 4 (Oct 70) p 571-578. (M)

Identification of key sources of parental stress and anxiety as identified in a 4 phase adaptational process of 65 families of children with cystic fibrosis. Phase-specific crises of child are identified with intervention strategies offered.



- \*4. Schild, Sylvia. "Parental Adaptation to Phenylketonuria," Dissertation Abstracts, 1968 29(4-A)p1296-1297.

Research to identify nature of stressors and effectiveness of adaption skills used by parents of children with PKU. Implications to professional persons identified.

5. Schild, Sylvia. "Parents of Children With PKU," Children Today Vol 1, No 4 (July-Aug 72) p 20-22.

Discusses factors of genetic transmission and dietary regime as unique stressors. Identifies need for total family support in order to achieve good parent-child relationship.

### Neurological

1. Cowie, Valerie. "Parental Counseling and Spina Bifida," Developmental Medicine and Child Neurology, Vol 9 No 1 (Feb 67) p 110-112. (M)

Discussion of needs for aggressive, effective social systems and prepared medical personnel to help parents cope with reactions to birth of defective child. Intervention strategies for initial introduction of defect to the parents postulated.

- \*2. Freeston, B. M. "An Enquiry Into the Effect of a Spina Bifida Child Upon Family Life," Developmental Medicine and Child Neurology Vol 13 No 4 (Aug 71) p 456-461.

Discussion of stressors parents of disabled child must cope with besides their own reaction to the disability, i.e., separation from child, transportation and time for hospital visits, family planning, extra marital complications, and financial factors. These are related to the availability of social systems to support family members and family cohesiveness. Data compiled from survey of 85 families of children under 4 years of age with Spina Bifida.

3. Hare, E. H., K. M. Laurence, Helly Paness, and K. Rawnsley. "Spina Bifida Cystica and Family Stress," British Medical Journal No 5516 (24 Sept 66) p 757-760. (M)

Study of 120 families of infants with major neurological defect using 4 sequential interviews during infant's 1st year of life. Explores reactions of parents to the event, how they were told, marital relationship, family planning and reactions of relatives. Implications for intervention identified.

4. Stanko, Barbara. "Crisis Intervention After the Birth of a Defective Child," The Canadian Nurse, Vol 69 No 7 (July 73) p 27-28. (M)

A mother describes her inner reactions to the medical staff and their handling of the parents and child after the birth of a defective baby.

5. Tew, Brian J. "Spina Bifida: Family and Social Problems," Special Education: Forward Trends, Vol 1 No 2 (June 74) p 17-20.

Review of recent research on the effect of a spina bifida child on the personal and social structure of a family. Covers long range as well as immediate effects with identification of developmental crisis points.

6. Tew, Brian J., H. Payne and K. M. Laurence. "Must a Family With a Handicapped Child be a Handicapped Family?," Developmental Medicine and Child Neurology, Vol 16 No 6, Supplement No 32 (74) p 95-98.

Investigation of the effect of having a severely defective child on the marital stability and satisfaction of 59 families immediately after the child's birth and 9 years later:

7. Walker, J. H., M. Thomas and I. T. Russell. "Spina Bifida -- and the Parents," Developmental Medicine and Child Neurology, Vol 13 No 4 (Aug 71) p 462-476.

Report on study of 107 families and their initial response to birth of child with spina bifida. Discusses perception of health care and other support systems. Identification of specific threats to the integrity of the family system. Comparison to other researcher's findings with identification of intervention needs.

8. Weller, S. D. V. "The Abnormal Child and His Parents," Nursing Mirror, Vol 135 (Dec 8, 72) p 26-29. (M)

A medical doctor discusses the importance of sensitivity to parental reactions when relating the facts to them in a realistic way. Principles of undergirding support of the parental decision for treatment or non-treatment of a severely defective newborn offered and illustrated with case examples.

9. Zachary, R. B. "Ethical and Social Aspects of Treatment of Spina Bifida," Lancet, No 7562, Vol 2 (Aug 3, 68) p 274-276.

Well supported discussion and analysis of factors affecting decisions for treatment and placement of infants born with spina bifida. Related to family relationships, community responses and educational difficulties.

### Orthopedic

- \*1. Blakeslee, Berton. The Limb-Deficient Child. Berkeley: U. of Calif. Press, 1973. Ch. 3, "The Psychosocial Problems," p 79-94. (M)

Discussion of the interrelatedness between past experience of parents and the hospital personnel's verbal and non-verbal behavior as inhibitors or facilitators of the grieving and adaptation process of parents of infants with orthopedic anomalies. Particular attention to self blame, and alienation. Analysis of behavioral manifestation with suggested intervention strategies.

2. Gurney, Wilma. "Congenital Amputee," in Ambulatory Pediatrics, ed. by Morris Green and Robert J. Haggerty, 1968. p 534-540.  
Developmental approach to discussing effect of congenital amputation on development of child. Much attention given to parental attitudes -- especially father.
- \*3. Mercer, Ramona T. "Mothers' Responses to Their Infants With Defects," Nursing Research, Vol 23 No 2 (March-April 74) p 133-137.  
Assessment of verbal and non-verbal behaviors of 5 mothers of visibly defective infants during 1st 3 months of infant's life. Identification of specific caretaking behaviors, attachment and aversion behaviors. Analysis of the behavior patterns supported via literature search.

Non-Specified, More Than One Disability,  
or Generally Applicable

1. Apgar, Virginia and Joan Beck. Is My Baby All Right? N.Y.: Pocket Book, 1972. 542 p. (L)  
Pediatrician and journalist discuss causes, prevention, symptoms, prognosis and treatment of birth defects for parents. Clear, specific, factual data. Includes section on genetic transmission. Parental reactions and community attitudes scattered throughout. Deals more with facts than feelings. 45 sources of help for parents at end of book.
2. Auerbach, Aline. "Group Education for Parents of the Handicapped," Children, Vol 8 No 4, (July-Aug 61) p 135-140.  
In depth discussion of factors affecting parental participation in group conferences with implications for intervention strategies. Discussion of emotions expressed and value of sessions to parents in their adaptational process. Analysis of group dynamics including leadership variables.
3. Babbitt, Paul H. "Appraisal of Parental Attitudes," Journal of Rehabilitation, Vol 30 No 1 (Jan-Feb 64) p 20-21.  
Conceptual discussion of stressors and inhibitors to successful parent-child interaction. Application to long-range effect on parent-child interaction patterns. Implications for counseling and research offered.
4. Bakwin, Ruth M. "Counseling the Parents of the Handicapped Child," J. of the American Medical Women's Association, Vol 20 No 8 (Aug 65) p 748-751.  
Discussion of the effect of parental attitudes and coping skill on the ability of the child to develop mature independence over time.

5. Barsch, Ray H. "The Handicapped Ranking Scale Among Parents of Handicapped Children," Am. J. of Public Health, Vol 54 No 9 (Sept 64) p 1560-1567.

Approximately 2500 individuals were asked to rank 10 disabling childhood conditions in order of severity. Subjects included professionals, lay persons and parents. The parents of disabled children indicated other conditions were more serious to cope with than the one their child experienced.

- \*6. Barsch, Ray H. The Parent of the Handicapped Child, Springfield, Ill.: Charles C. Thomas, 1968. 433 p.

Extremely comprehensive text based heavily on replicable research 1959-1963. Very readable analysis and presentation of data. Covers broad spectrum of intra and extra-familial stressors with subsequent coping patterns. Also explores practical aspects of living with child such as responsibilities, sex education, community relations, discipline. Data gathering tools included many graphs, charts.

- \*7. Baum, Marian Hooper. "Some Dynamic Factors Affecting Family Adjustment to the Handicapped Child," Exceptional Children, Vol 28 No 8 (Apr 62) p 387-392. Also in: Gowan, John Curtis, et al. The Guidance of Exceptional Children. N.Y.: David McKay Co., Inc., 1972. p 395-403.

In depth study of immediate emotional responses of parents to birth of defective child using Bowlby's conceptual frame. Discussion of effect on ego identity, interpersonal relationships, and parent-child relationships. Offers conceptual framework to aid professional persons to construct realistic goal-oriented intervention strategies. Supported with extensive literature search.

8. Bentovim, Arnon. "Emotional Disturbances of Handicapped Pre-School Children and Their Families -- Attitudes to the Child," British Medical Journal, No 5826 Vol 3 (Sept 2, 72) p 579-581.

A physician uses a developmental approach to compare reactions of parents to birth of normal child vs. defective infant. Implications to the parent-child interaction and bonding process discussed. Factors affecting parental coping skills during child's early years discussed.

9. Boone, Donald R. and B. H. Hartman. "The Benevolent Over-Reaction," Clinical Pediatrics, Vol 11 No 5 (May 72) p 268-271.

In depth discussion of how a parent's perception of a child as being defective can lead to over-protective behavior which ultimately leads to pseudoretardation due to experience deprivation. Supported with case studies from Developmental Evaluation Clinic of Western North Carolina, Inc. Intervention strategies offered. Stressing need for prophylactic counseling to be initiated immediately by the identifier of child's disability.

10. Branson, Helen Kitchen. "When a Defective Infant is Born," Bedside Nurse, Vol 3 No 11 (Nov 70) p 18-19. (M)

Discussion of initial reactions of parents to birth of defective infant. Suggests intervention strategies to help parents plan for future.

- \*11. Bryant, John E. "Parent-Child Relationships: Their Effect on Rehabilitation." Journal of Learning Disabilities, Vol 4 No 6 (June-July 71) p 325-329.

Conceptual exploration of the 3 most commonly observed parental reactions. Discussion of etiology, manifestations, compensations with implications for effect on habilitation and parental counseling.

- \*12. Buscaglia, Leo. The Disabled and Their Parents: A Counseling Challenge. Thorofare, N.J.: Charles B. Slack, Inc., 1975. 393 p.

9 chapters devoted to in depth exploration of cultural and developmental factors influencing parental and family reactions to the birth of a physically disabled child. Rest of book looks at the disabled individual and counseling challenges. Extensive bibliography.

- \*13. Butani, Pushpa. "Reactions of Mothers to the Birth of an Anomalous Infant: A Review of the Literature," Maternal-Child Nursing Journal, Vol 3 (Spr 74) p 59-76.

Extensive well-organized review of 65 articles published between 1937 and 1970 for (1) factors influencing maternal reactions and (2) reactive maternal behaviors. Identifies need for more empirical research to be conducted in immediate postpartal period.

14. Byers, Mary Lou. "Grief Work of a Mother of a Child Born with Defects." ANA Regional Clinical Conference, Vol 3, 1965. p. 45-53. (M)

Case study shares details of intra and interpersonal experiences affecting behavior patterns and bonding process of a mother to her child. Explores the evolution of a mother's reactions from revulsion to acceptance of her infant with a dislocated hip.

- \*15. Carr, E. F. and T. E. Oppé. "The Birth of an Abnormal Child: Telling the Parents," Lancet, Vol 2 No 733 (Nov 13, 71) p 1075-1077. (M)

Discussion of the problems of communicating news of defect to the parents. Expected reactions identified with suggestions of approaches to aid acceptance. Relationship of approaches to future parent-child relationships emphasized.

16. Clay, Cherie. "There is Something Wrong With Your Baby." In: Current Practice in Obstetric and Gynecologic Nursing, by Leota McNall and Janet Galeener. St. Louis: C. V. Mosby Co., 1976. p. 146-150. (M)

A nurse very sensitively and personally applies Kubler-Ross' and Kavanaugh's theories on grief and loss to birth and death of her disabled infant. Particular focus on her reactions to interactions with staff, visitors, other mothers and baby. Discusses struggle to maintain contact with reality and need for more effective communication.

- \*17. Cohen, Pauline C. "The Impact of the Handicapped Child on the Family," Social Casework, Vol 43 No 3 (Mar 62) p 137-142.

A social worker discusses the adjustments parents of disabled children have to make and how reactions and coping skills may effect quality of family life. Implications for intervention strategies to facilitate the coping process.



18. Cook, John J. "Dimensional Analysis of Child-Rearing Attitudes of Parents of Handicapped Children," Am. J. of Mental Deficiency, Vol 68 No 3 (Nov 63) p 354-361.

187 mothers of physically disabled children were administered the PARI. The results were superimposed on a two-dimensional schema using Fels parent behavior scale with hostility-love and autonomy-control axis. Significant differences in parental attitudes are identified in relationship to severity and type of disability.

19. Cruickshank, William M. Psychology of Exceptional Children and Youth. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1971. 624 p.

In depth discussion of psychological components constituting loads and powers to children with specific disabilities. Parental reactions and influence on child's psychological health scattered throughout book.

\*20. Cummings, S. Thomas, Helen C. Bayley and Herbert E. Rie. "Effects of the Child's Deficiency on the Mother: A study of Mothers of Mentally Retarded, Chronically Ill and Neurotic Children," Am. J. of Orthopsychiatry, Vol 36 No 4 (July 66) p 595-608.

240 mothers of defective children were interviewed and tested for adaptive competence in areas such as self-esteem and child rearing attitudes. Mothers of mentally defective children show more psychological stress than mothers of physically defective children.

\*21. D'arcy, Elizabeth. "Congenital Defects: Mother's Reactions to First Information," British Medical Journal, No 5621 Vol 3 (Sept 28, 68) p 796-798. (M)

Presentation of how, when and from whom 694 mothers first learned about an infant's defect and how these and other variables effected the adaptation process in the immediate post-partal period as well as years later. Many implications for intervention strategies inferred.

\*22. Davis, Fred. "Impact of Chronic Illness on the Family as a Whole," The Case of Children With Chronic Illness. Report of the 67th Ross Conference on Pediatric Research, Columbus, Ohio: Ross Laboratories, 1975. p 49-56.

Identification and discussion of the stigmatizing and isolating effect of having a disabled child on the family unit. Exploration of changes in social interaction patterns and effect on long range self esteem, intra- and extra-familial adjustment patterns. Panel members responses with application to activities of daily living and community-focused intervention strategies to reduce alienation.

23. Dow, Thomas E. "Family Reaction to Crisis," Journal of Marriage and the Family, Vol 27 No 3 (Aug 65) p 363-366.

Analysis of relationship between structure and reaction patterns of 58 families with a physically disabled child. Discussion of factors contributing to short and long range dysfunction.

24. Elfert, Helen. "The Nurse and the Grieving Parent," The Canadian Nurse, Vol 71 No 2 (Feb 75) p 30-31. (M)

Discussion of how normal anxiety and guilt of the parent-hood experience can become magnified and distorted when facing illness of child. Uses Futterman's frame for explaining 5 steps of anticipatory mourning. Discusses need to accept parent's feelings and behavior in perspective of the crisis.

- \*25. Fischman, Claire A. and Daniel B. "Maternal Correlates of Self-Esteem and Overall Adjustment in Children With Birth Defects," Child Psychiatry and Human Development, Vol 1 No 4 (Sum 71) p 255-265.

Research design to correlate 8 maternal variables with self esteem and overall adjustment of 80 disabled children 8 - 14 years of age. Three of the variables involve retrospective descriptions of mothers' reactions immediately following discovery of defect.

- \*26. Fotheringham, John B. and Dorothy Creal. "Handicapped Children and Handicapped Families," International Review of Education, Vol 20 No 3 (74).

Explores factors affecting the establishment of homeostasis in the dyadic relationship between disabled child and his family via literature review. Three family-oriented programs suggested to maximize child's and family's potentials.

27. Fox, Mervyn A. "Talking With Parents," Nursing Times, Vol 68 No 49 (Dec 7, 72) p 1564.

Discussion of how professionals can compassionately and competently meet parents' affective needs following crisis of birth of defective child.

- \*28. Freeman, Roger D. "Review of Medicine in Special Education; The Crisis of Diagnosis: Need for Intervention," The Journal of Special Education, Vol 5 No 4 (Wint 71) p 389-414.

In depth review of literature with comparison of conceptual frames, discussion of variables including predisposing factors, siblings, relatives. Outline of principles of management reasons for failure of medical personnel to intervene appropriately. Section on reaction of the child to his own disability as related to parental attitude. Extensive bibliography.

- \*29. Gardner, Richard A. "The Guilt Reaction of Parents of Children With Severe Physical Disease," Am. J. of Psychiatry, Vol 126 No 5 (Nov 69) 636-644. Also in: Noland, Robert L. Counseling Parents of the Ill and the Handicapped, Springfield, Ill.: Charles C. Thomas, Pub., 1971. p 27-43.

A child psychiatrist challenges the classical guilt process of Freudian psychoanalytic theory through intensive interview and testing of 23 parents of physically disabled children. Offers the hypothesis that guilt may also represent an attempt to control the uncontrollable. Presents and discusses 4 psychopathological process models.

30. Gardner, Richard A. "The Use of Guilt as a Defense Against Anxiety," Psychoanalytic Review, Vol 57 No 1 (1970) p 124-136.

In depth developmental approach to the phenomena of guilt reactions with brief application to parents of disabled children. Relating to religious beliefs.

31. Gillis, Leon. "Physically Handicapped Children" Nursing Times, Vol 61 No 12 (Mar 19, 65) p 382-383. (M)  
Discussion of approaches to working with mothers of congenitally defective newborns based on anticipation of behavior patterns.
32. Gonzalez, Mary Theresa. "Nursing Support of the Family With an Abnormal Infant," Hospital Topics, Vol 49 No 3 (Mar 71) p 68-69. (M)  
Brief discussion of overt behavior patterns parents may exhibit. Discussion of appropriate verbal and non-verbal communication skills nursing staff may implement to facilitate parental communication and activation of positive coping skills.
- \*33. Gordon, Norman B. and Bernard Kutner. "Long Term and Fatal Illness and the Family," Journal of Health and Human Behavior, Vol 6 No 4 (Wint 65) 190-196. (M)  
Discussion of the impact of chronic or fatal illness on the stability of the family. In depth discussion of implications to the role of the family. Conceptual frame offered for parental counseling and identification of specific research needs.
34. Gordon, Sol. "A Bill of Rights for Parents," Academic Therapy, Vol 11, No 1 (Fall 75) p 21-22. (L)  
Director of the Institute for Family Research encourages parents of disabled children to meet their own emotional needs as individuals. Infers the child as well as parent will benefit from a positive approach to living expressed in 22 axioms.
- \*35. Green, Morris, and Mary Ann L. Durocher. "Improving Parent Care of Handicapped Children," Children, Vol 12 No 5 (Sept-Oct 65) p 185-188.  
Discussion of the parent education program at the James Whitcomb Riley Hospital, Indianapolis, Ind., which was inaugurated on the premise that disabled children exhibited preventable secondary handicaps traceable to the family interaction patterns. By recognizing the parents as the "most important member of the treatment team," staff developed multidisciplinary programs to educate and support parents as one facet of treating the child.
36. Greer, Bobby G. "On Being the Parent of a Handicapped Child," Exceptional Children, Vol 41 No 8 (May 75) p 519. (L)  
Brief discussion of sociological factors affecting a parent's ego identity following birth of defective child. Call to form parent groups for support.
- \*37. Heisler, Verda. A Handicapped Child in the Family: A Guide for Parents. N.Y.: Grune and Stratton, 1972. 160 p. (L)  
A book written specifically for parents by a physically disabled psychologist to stimulate heightened awareness of the meanings and resolution of their reactions to their child's disability and the problems of parenting. Presentation and exploration of case studies to aid self-exploration and identification of inner resources to external stressors. Both theoretical and pragmatic in approach. Challenge to use the situation as a stepping stone to higher personal growth.



38. Holdaway, David. "Educating the Handicapped Child and His Parents," Clinical Pediatrics, Vol 11 No 2 (Feb 72) p 63-64.

Conceptual discussion of relationship of parental coping skills to disabled child's chances of attaining maximal functioning level and actualizing of potentials. Plea for educational consultants and facilities to be made available to parents of disabled infants.

\*39. Howell, Sarah Esselstyn. "Psychiatric Aspects of Habilitation," Pediatric Clinics of North America, Vol 20 No 1 (Feb 73) p 203-219.

In depth discussion of the impact of a defect on the ego identity, coping skills and interpersonal relationship of the child, family members and health care team members. Also explores diagnostic methods and approaches to psychiatric intervention methods.

\*40. Irvine, Elizabeth E. "The Risks of the Register: Or The Management of Expectation," in The Child in His Family, Vol III, Ed. by E. James Anthony and Cyrille Koupernik, N.Y.: John Wiley & Sons. p 181-191.

Discussion of how maternal adjustment affects infant's emotional development. Identification of factors affecting adjustment and some intervention strategies.

41. Johns, Nan. "Family Reactions to the Birth of a Child With a Congenital Abnormality," The Medical Journal of Australia, Vol 1 No 5 (Jan 30, 71) p 277-282.

Study of 12 families over 6 months to identify early and later reactions to birth of defective infant. Identification of factors affecting coping skills and fears for future of child and self. Illustrated with case studies. Implications for intervention identified.

\*42. Jordon, Thomas E. "Research on the Handicapped Child and the Family," Merrill-Palmer Quarterly, Vol 8 No 1 (Jan 62) p 243-260.

Review of the literature for major conceptual approaches to description and understanding of parental responses and behavior patterns. Differentiates responses of individual family members according to roles. Related to constructs of crisis theories, religion, attitudes towards independence and nurturiveness. Identifies areas for further research. Extensive bibliography.

\*43. Kaplan, Bert L. "Counseling With Mothers of Exceptional Children," Elementary School Guidance and Counseling, Vol 6 No 1 (Oct 71) p 32-36.

Discussion of unresolved emotional reactions to birth of defective child and effect upon parent-child and parent-school relationship. Explores some of the causes and implications of anger, guilt and self-depreciation with some conceptual approaches to resolution.

\*44. Kennedy, James F. "Implications of Grief and Mourning for Mothers of Defective Infants," Dissertation Abstracts International, Vol 31 (1-A) p 472-473.

Investigation of the grief process as exhibited by mothers of defective infants. Behaviors of 3 phases identified with sequencing and time limits identified using Lindemann's model. Implications identified.

- \*45. Kennedy, James F. "Maternal Reactions to the Birth of a Defective Baby," Social Casework, Vol 51 No 7 (July 70) p 410-416.

Literature review and research is presented to explore whether the demands of caring for a defective infant may delay resolution of the grief and mourning process in the mother. Explores both behavior pattern progression and time limitations of uncomplicated grief process. Physical presence of defective infant in mother's care was found to interrupt the grief process.

- \*46. Kennell, John H. and Alice R. Rolnick. "Discussing Problems in Newborn Babies with Their Parents," Pediatrics, Vol 26 No 5 (Nov 60) p 832-838. (M)

Presentation and analysis of 5 case studies involving physically defective newborn infants and their mothers. Identification and discussion of specific intervention strategies for physician.

47. Kogan, Kate L. and Nancy Tyler. "Mother-Child Interaction in Young Physically Handicapped Children," Am. J. of Mental Deficiency, Vol 77 No 5 (Mar 73) p 492-497.

Mother-child interaction patterns of 10 preschool age children with physical disabilities is compared with mother-child patterns of children who are mentally retarded. Identifies some habitual interactive patterns and communication styles utilized by the family to perform daily living activities.

- \*48. Kvaraceus, William and E. Nelson Hayes. If Your Child Is Handicapped. Boston: Porter Sargent Pub., 1969. (L)

A collection of personal accounts of parents of exceptional children. Written for parents of exceptional child as well as professional persons who work with them. Covers broad spectrum of aspects the parents confront in rearing the exceptional child from parental acceptance to child acceptance; discipline to religious training; preparation of child for leadership to preparation for death; culminating chapter stresses need to focus on family as much as child, early intervention. Excellent summary of implications.

49. Lancaster, Jean and Florence Bright Roberts. "Impact of Intensive Care on the Maternal-Infant Relationship," in: Korones, Sheldon B. High-Risk Newborn Infants; The Basis for Intensive Nursing Care, St. Louis: The C. V. Mosby Co., 1972. p 217-222. (M)

Two nurses explore the dual effect of loss of expected child and separation from high risk or defective child on maternal attitudes toward neonate. Offers conceptual and specific intervention strategies to reduce impact of stressors.

- \*50. Lindemann, Erich. "Acute Grief: Symptoms and Management," Child and Family, Vol 4 (Fall 65) p. 73-85

Description and discussion of somatic and psychic characteristics accompanying acute grief following loss of significant other. Differentiation of normal from pathological grieving. Conceptual frame applicable to any loss. Illustrated with case examples.

51. Linder, Ralph. "Mothers of Disabled Children -- the Values of Weekly Group Meetings," Developmental Medicine and Child Neurology, Vol 12 No 2 (Apr 1970) p 202-206.

Presents and discusses how weekly group meetings by mothers of disabled children helped to ease the pain of alienation and enable most of the mothers to adapt to the stresses of living with a disabled child more successfully.

52. Lipton, May. "Birth Defects Today -- Their Impact Upon the Family, the Patient and Society. Part II," The Journal of School Health, Vol 39 No 1 (Jan 69) p 40-42.

Presentation of statistics regarding prevalence of birth defects in the U.S.A. by The National Foundation, with discussion of the impact on family and community. Specific strategies for prevention, community education and education offered.

\*53. Love, Harold D. Parental Attitudes Toward Exceptional Children. Springfield, Ill.: Charles C. Thomas, 1970. 167 p.

Based on presupposition that the child's emotional adjustment to life is related to the parent's adjustment and ability to cope with the child and disability. Discusses cause and resolution of shock, refusal, guilt, bitterness, envy and rejection. Recognizes evaluational patterns of adjustment (p 27-40). Discusses differences of reaction according to type of disability, family member. Indicates mother reacts more strongly than father due to provision of intrauterine environment and frequency of contact. Bibliography following each chapter.

54. Lowenfeld, Berthold. Our Blind Children: Growing and Learning With Them, 3rd ed. Springfield, Ill.: Charles C. Thomas Co., 1971. p 106-115. (L)

Discusses 5 distinct long-term parental attitudes categorized by Sommers in 1944. Speaks heavily of guilt. Describes and analyzes behavior patterns fostered by each attitude. Stresses effect of early parental attitudes on long-range parent-child relationship. Continues to discuss cultural and personal factors affecting parental attitude and the child's self attitude.

55. MacKeith, Ronald. "The Feelings and Behavior of Parents of Handicapped Children," Developmental Medicine and Child Neurology, Vol 15 No 4 (Aug 73) p 524-527.

Conceptual, yet specific overview of immediate and long range reaction of parents to the birth of disabled child with recognition of factors influencing the behaviors. Identifies crisis periods on a longitudinal perspective. Identification of factors significant to decision to institutionalize.

\*56. Mandelbaum, Arthur and Mary Ella Wheeler. "The Meaning of a Defective Child to Parents," Social Casework, Vol 41 No 7 (July 60) p 360-367.

Discussion of factors affecting parental coping skills as observed at the Children's Services of the Menninger Clinic, Topeka, Kansas. In depth discussion of defense patterns with identification of specific intervention strategies to reduce stress and facilitate adjustment.

57. Martin, Harold P. "Parental Response to Handicapped Children," Developmental Medicine and Child Neurology, Vol 17 No 2 (Apr 75) p 251-252.

Brief discussion of factors influencing parental response and coping skills following the birth of a defective child.

58. May, E. "Telling the Parents," Lancet, No 7878 Vol 2 (Aug 24, 74) p 471. (M)

Brief letter to medical personnel to encourage them to tell the parents together about an infant's defect and not force the father to tell the mother.

- \* 59. McCollum, Audrey T. Coping with Prolonged Health Impairment in Your Child. Boston: Little, Brown and Co., 1975. 240 p. (L)

Author-to-parent discussion of inner reactions to birth and life with a disabled child. Fears, anxieties, social problems, relationships to family members, responses, medical personnel, discussed in terms of normalcy of reactions and how to mobilize coping skills. Separate chapters devoted to parenting disabled children of various developmental phases. Discussion of family planning and resources to assist both parents and child. Appendix lists agencies offering information on help.

60. McDonald, Eugene T. "Understanding Parents' Feelings," reprint A-187, 1:1M:1063. Chicago: The National Easter Seal Society for Crippled Children and Adults. n.d. 4p. (L)

Discussion of questions, fears and emotions parents of defective newborns experience with their characteristic overt expression. Identification of strategies to aid adaptation to the situation of parenting a disabled child. Stresses need for open communication and recognition of reactions and feelings as normal.

61. McDonald, Eugene T. Understanding Those Feelings. Pittsburgh: Stanwix House, Inc. 1962. 196 p. (L)

In depth exploration of etiology and expression of parental feelings upon learning of and living with physically disabled child. Approaches the feelings as universal and normal. Uses developmental, holistic, family approach to discussion of specific areas of inter- and intra-personal relationships of parents. Theorizes that pathology occurs only if feelings are not recognized, understood or are misdirected. Goal is prevention of handicapped family due to presence of disabled child. Very specific professional and parental intervention strategies identified and discussed.

- \*62. McMichael, Joan K. Handicap: A Study of Physically Handicapped Children and Their Families. Norwich, Great Britain: Fletcher and Sons, Ltd., 1971. Chapters 7, 8 & 9, p 86-128.

Study of 50 families for in depth exploration of factors affecting coping behaviors of parents and siblings. Attention to multiply handicapped infant with extended diagnostic time span. Amply illustrated with case studies. Discussion of emotional adjustment of specific family members. Long range as well as immediate reactions identified. Effect on family interaction patterns.

- \*63. Meadow, Kathryn P. and Lloyd Meadow. "Changing Role Perceptions for Parents of Handicapped Children," Exceptional Children, Vol 38 No 1 (Sept 71) p 21-27.

Explores factors affecting a parent's responses to the birth of a physically defective child and the subsequent effect on parental ability to successfully assist the child to positive socialization and adjustment to disability. Includes religious orientation and ordinal position.



64. Moore, Mary Lou. The Newborn and the Nurse. Philadelphia: W. B. Saunders, 1972. p 131-138. (M)

Nurse offers overview of factors affecting parental responses to birth of infant with special problems. Discusses in detail effect of separation from infant on maternal attitudes and suggests correlation with emotional disorders of child later in life.

65. Noland, Robert L. Counseling Parents of the Ill and the Handicapped. Springfield, Ill.: Charles C. Thomas Pub., 1971. 606p.

A collection of 55 articles dealing with a wide variety of stressors and variables affecting parents coping skills. Many identify and discuss intervention strategies for specific disabling situations. Focus appears to be maintaining integrity of family system.

66. "Physician's Aid for Parents of the Handicapped," Medical Tribune, Sept. 22, 1971. p 18. (M)

Report on Dr. Ronald MacKeith's address at an international symposium on "The Ecology of the Child and Human Development" in Miami, Florida. Synopsis of the major emotional reactions of parents. Brief discussion of behavior patterns.

67. Owens, Charlotte. "Parents' Reactions to Defective Babies," Am. J. of Nursing, Vol 64 No 11 (Nov 64) p 83-86. (M)

A psychiatric nurse encourages early parental involvement in care of a disabled infant in a supportive environment and as a means to aid acceptance of the reality of the situation. Discusses extensively the nurse's role in aiding the mother-infant bonding process.

68. Parent Counseling: Exceptional Child Bibliography Series. ED 054573. Arlington, Va. : Council for Exceptional Children, Feb. 1971. 20 pgs.

Abstract of 76 references dealing with parental counseling. References for both professional and parent included. High percentage of retardation. Minimal data on parental attitudes. Indexed.

69. Parent Education: Exceptional Child Bibliography Series. ED 053513. Arlington, Va.: Council for Exceptional Children, 1971. 20 pgs.

Abstract of 92 references written for or about parents of exceptional children. Most are oriented to the realities and practicalities of daily living. Minimal reference to parental attitudes. Indexed.

- \*70. Parent Education/Parent Counseling: A Selective Bibliography. Exceptional Child Bibliography Series No. 631. ED 069070. Arlington, Va.: Council for Exceptional Children, Aug. 1972. 32 pgs.

Abstracts of 98 citations of references with index for professional and parent usage. Many dealing with parental attitudes in part or all of entry.

- \*71. Poznanski, Elva O. "Emotional Issues in Raising Handicapped Children," Rehabilitation Literature, Vol 34 No 11 (Nov 73) p 322-326, 352.

In depth discussion by a psychiatrist of emotional responses of parents to pregnancy and subsequent birth and rearing of disabled child. Discusses internal coping, overt behavior and specific emotional issues parents must face and cope with.

- \*72. Pringle, M. L. Kellmer. "The Emotional and Social Adjustment of Physically Handicapped Children: A Review of the Literature Published Between 1928-1962," Educational Research, Vol 6 No 3 (June 64) p 207-215.

Director of the National Bureau for Co-operation in Child Care extracts salient features from 34 years of literature. Organizes presentation into 6 study areas for conciseness and clarity: (1) General descriptive studies (2) Comparative studies (3) Education and achievement (4) Therapy and rehabilitation (5) Case studies and (6) Relationship between adjustment and maternal/parent attitudes. 50+ references. Indicates that the majority of studies conclude that child's adjustment to disability is primarily dependent on parental attitudes and relationship.

73. "Professionals: Are You Listening?," Closer Look, (Wint 76) p 1, 9-11.

An open letter to professional personnel for a more sensitive awareness of the parent's emotional reactions upon learning of a child's disability. Ways to show acceptance of parent as individuals and offer cooperative continuity of care for mutual respect identified.

- \*74. Richmond, Julius B. "The Family and the Handicapped Child," Clinical Proceedings. Children's Hospital National Medical Center, Vol 29 No 1 (Jan 73) p 156-164.

In depth discussion of psychological adaptive processes parents of disabled children experience. Covert and overt behavior as well as relationships between manifestations of reactions discussed. Conceptual guidelines for intervention strategies offered.

- \*75. Ross, Alan O. The Exceptional Child in the Family. N.Y.: Grune & Stratton, 1964. 230 pgs.

Based on the presupposition that a child's ego identity and subsequent success in coping with life is reflective of the family's identity and coping ability. A psychologist uses conceptual approach to help professional persons understand the unique stressors facing an exceptional family in a complex, changing society. Emphasizes the individuality of family dynamics and need for principles not prescriptions for intervention. Reaction explanation oriented toward Freudian depth psychology (p 51-70). Indicates mother has more difficulty with initial adjustment, father with child's school entrance. Interdependent nature of reactions of family members explored and supported. Brief annotated bibliography for parental referral included. Extensive bibliography.

76. Schwartz, Lawrence H. and Jane Linker Schwartz. The Psychodynamics of Patient Care. Englewood Cliffs, N.J.: Prentice-Hall, 1972. p 71-76. (M)

Doctor and nurse discuss immediate responses of mother to birth of defective child. Stresses need for nutritive support to aid coping process during hospitalization and after discharge. Brief discussion of long range effects on parent-child relationship.

77. Short-Randle, John. "The Care of the Child With a Long-Term Handicap," The Medical J. of Australia, Vol 2 No 12 (Sept 20, 69) p 604-606. (M)

Discussion of various factors influencing the child's development, including parental attitudes and community. Identification of implications for futuristic oriented intervention.

78. Solnit, Albert J. and Mary H. Stark. "Mourning and the Birth of a Defective Child," The Psychoanalytic Study of the Child, Vol 16 (1961). p 523-537.

In depth discussion of development of grief reaction of mothers to birth of defective child as response to loss of "wished-for" child. Illustrated with case studies of retarded children. Implications for intervention offered.

79. Spock, Benjamin. On Being a Parent ... of a Handicapped Child. Chicago: The National Society for Crippled Children and Adults, Parent Series #8, 1961. 18 pgs. (L)

Sensitive, practical discussion written for parents. Explores sociological and personal factors affecting parental reactions to the defective infant. Interspersed with his own thoughts, reactions, case examples and evolution of ideas regarding reactions and placement. Positive, normalcy aspects of child emphasized with sources of support agencies listed.

80. Spock, Benjamin and Marion O. Lerrigo. Caring for Your Disabled Child. N.Y.: The Macmillan Co., 1965. Part I "Living With Disability". p 2-46. (L)

Very positive discussion of how to recognize and accept inner reactions to child's disability as normal responses shared by other parents. Parental acceptance level related to child's adjustment to his disability. Discusses strategies to maximize potentials of each family member and reduce stigmatizing effect in community relationships.

81. Strauss, Anselm L. Chronic Illness and the Quality of Life. St. Louis, Mo.: The C. V. Mosby Co., 1975. Chapter 8 "The Family in the Picture". p 66-67. (M)

Recognizes the parents and siblings as an integral part of the ill child's milieu. Encourages "sensitive" attention to reactions of entire family as part of client therapy.

- \*82. Telford, Charles W. and James M. Sawrey. The Exceptional Individual. Englewood Cliffs, N.J.: Prentice-Hall, Inc. 1972.  
 "Family and Personal Problems of Exceptional Individuals," p 96-123.

Discussion of the impact of a disabled child on the family system. Identification and analysis of specific factors affecting role relationships. In depth analysis of emotional coping mechanisms and overt behavior patterns. Explores self concept of child from a developmental perspective. Identifies specific counseling strategies.

- \*83. Tisza, Veronica. "Management of the Parents of the Chronically Ill Child," American Journal of Orthopsychiatry, Vol 32 No 1 (Jan 72) 53-59. (M)

Psychiatrist uses a conceptual framework to discuss emotional response of parents to the news of a disabling chronic condition of an infant or child. Explores in detail the need for sensitivity to these responses for construction of therapeutic intervention strategies.

84. Von Krevelen, D. Ann. "The Problem of Communicating the Diagnosis to the Parents," Acta Paedopsychiatrica, Vol 32 No 2 (Feb 65) p 33-34. (M)

Child psychiatrist observes that parents are often aware of diagnosis before discussion with professional persons. Professional warned to approach the parents gradually, in several sessions to aid communication and acceptance.

85. Von Schilling, Karin C. "The Birth of a Defective Child," Nursing Forum, Vol 7 No 4 (68). p 424-439. (M)

Discussion of how the hospital obstetrical unit personnel can influence a mother's feelings of isolation and stigma following the birth of a defective child. Discussion of mother's coping skills and long range effects of intervention strategies on family life.

86. Voysey, Margaret. "Impression Management by Parents With Disabled Children," J. of Health and Social Behavior, Vol 13 No 1 (Mar 72) p 80-89.

General discussion of the stressors to ego identity in parents of disabled children, particularly in regards to interaction behaviors with child, community and professionals. Compares to normal developmental tasks of parenthood. Explores relationship of behavior patterns to degree of role identity in regards to responsibility and power. Implications related to parental competencies.

- \*87. Warren, Sue Allen. "The Distressed Parent of the Disabled Child," in: Problems in Psychotherapy: An Eclectic Approach, ed. by Walter G. Klopfer and Max R. Reed. N.Y.: John Wiley & Sons, 1974. p 125-153.

In depth exploration and analysis of factors affecting parental adjustment to birth of disabled child. Cross-cultural and historical views shared. Intervention strategies shared as case studies. Extensive literature review used to support.



- \*88. Wentworth, Elsie H. Listen to Your Heart. Boston: Houghton Mifflin Co., 1974. 262 pgs. (L)

A child psychologist and educator of exceptional children, who is also the mother of a physically disabled, mentally retarded daughter, extensively discusses basic affective reactions to the birth of a defective child, why the attitudes occur, how they express themselves in relationship to others and own ego identity. Separate sections deal with various family members. Shares ideas on how parents can cope with their own reactions, improve interpersonal relationships and maintain self esteem. Appendix lists resources for additional assistance.

89. Wilson, James L. "The Effect on the Whole Family of a Child With a Severe Birth Defect," in: Birth Defects, ed. by Morris Fishbein, Philadelphia: J. B. Lippincott, 1963. p 32-37. (M)

Identification of factors affecting both short and long-range reactions and adaptations of the parents to the birth of a defective child. Identification and discussion of overt behavior patterns with suggestions for appropriate, positive intervention strategies. Comparison of differences of parental stressors with physically vs. mentally disabled child.

- \*90. Zuk, G. H. "The Cultural Dilemma and Spiritual Crisis in the Family With a Handicapped Child," Exceptional Children, Vol 28 No 8 (Apr 62) 405-408.

Psychologist discusses the relationship between anger and guilt reactions in parents of defective children with factors influencing their manifestation. Review of literature with discussion of influence of religious beliefs on coping and behavior patterns.

## AUTHOR INDEX

## Key to index abbreviations:

- B - Blind
- C - Cardiac
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## SUBJECT INDEX

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